



Strategies for the Future

Long-Range Plan Report Phase 2: 2001-2003

DECEMBER 1, 2000

Planning for the
Services and Supports
Needed by People with
Developmental Disabilities
and Their Families in
Washington State — RCW 71A.12.170

The Division of
Developmental Disabilities



Washington State
Department of Social
& Health Services

REPORT TO THE LEGISLATURE

STRATEGIES FOR THE FUTURE

Long-Range Plan Report Phase II: 2001-2003

**PLANNING FOR THE SERVICES AND
SUPPORTS NEEDED BY PEOPLE WITH
DEVELOPMENTAL DISABILITIES AND THEIR
FAMILIES IN WASHINGTON STATE**

RCW 71A.12.170

Department of Social and Health Services
Health and Rehabilitative Services Administration
Timothy R. Brown, Ph.D., Acting Assistant Secretary

December 1, 2000

Prepared by:
Division of Developmental Disabilities
Linda Rolfe, Acting Director



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Washington State
Department of Social
& Health Services

Dennis Braddock, Secretary

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Services Administration***

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Acknowledgments

The Division of Developmental Disabilities (DDD) wishes to acknowledge contributions of the DDD Strategies for the Future Stakeholder Workgroup and subgroups in preparation of the Phase II Long-Range Plan.

The Stakeholder Workgroup members have been working in conjunction with the Division since June 1997. In February 1998, seventy-seven additional people joined the planning process to form 4 workgroups that submitted recommendations to the Stakeholder Workgroup. They selflessly participated in countless hours of issue mediation, research review, and consensus building. Without their leadership and perseverance, this planning effort could not go forward.

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Executive Summary

In recent years, people with developmental disabilities in Washington State and the people allied with them have been working to create a shift in how supports and services are offered. In 1997, Lyle Quasim, Secretary of the Department of Social and Health Services (DSHS), appointed the Strategies for the Future Stakeholder Workgroup (the Stakeholder Workgroup). Its primary mission was to build consensus among its members in order to advise the DSHS/Division of Developmental Disabilities (the division) on development of a strategic plan for the future of developmental disability services. Consensus was reached on the principle of individual choice and self-determination to guide future service delivery.

Current law directs the division, in conjunction with the Stakeholder Workgroup, to make recommendations to the legislature on how to best meet the needs of people with developmental disabilities and their families, today and in the future. DSHS will submit three reports to the legislature in December 1998, 2000, and 2002.

In December 1998, the division submitted Strategies for the Future Long-Range Plan Phase I Report to the Washington State Legislature. The report shared an estimate on unmet service needs, proposed a multi-biennial funding plan to meet these needs, and outlined an approach for system restructuring based on an individual choice and self-determination service delivery philosophy.

The division is now, in December 2000, submitting the Strategies for the Future Long-Range Plan Phase II Report to the legislature. This report is based on the contributions of over one hundred and twenty people who worked together in special topic workgroups with co-chairs from the Stakeholder Workgroup and the division. Recommendations from the topic workgroups went to the Stakeholder Workgroup for consideration, and those adopted were forwarded to the division, forming the backbone of this Phase II Report. While this report's primary focus is on the activities of the division and the Stakeholder Workgroup for the next two or three years, the long range planning effort will continue to work out system restructuring issues, including statutory change recommendations, and to implement choice and self-determination statewide by June 30, 2007.

Washington's focus on choice and self-determination comes as a result of years of committed work by hundreds of individuals with developmental disabilities, their families and friends, legislators, advocates, providers, and social service staff. A hallmark of this approach is the ability of people with developmental disabilities to make choices about their living conditions and supports. A primary tool in accomplishing this is individual control of service dollars, with each person or family having a budget that is portable. Portability allows the person to direct funds among options he or she chooses, and to make changes as desired—for example, choosing a different living or employment situation.

The Phase II Report recommends a two-part approach to developing individual budgets. A general allocation would be available to all eligible persons, with some variation for

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children ages three through twenty who are funded through the school system. A second specialized allocation may be added after an individualized assessment process for those people who find that their general allocation is insufficient to purchase needed services. The Stakeholders Workgroup did not recommend using an individual assessment process for all eligible persons since this process would be expensive to administer. In addition, the division estimates that approximately eighty percent of people currently served would have adequate dollars to meet their needs within the proposed general budget amount.

To prepare for implementing this flexible individual budget approach, two initiatives are presented in this Phase II Report. The first, already underway and continuing into the 2001-2003 biennium, is to test and refine the assessment instrument. The second, proposed for the 2001-2003 biennium, is to pilot individual budgets and other choice and self-determination components. The pilot is proposed for one geographic area of the state. The purpose of the pilot is to test each component of a choice and self-determination system to determine what works best for people and their families.

After reaching consensus on using choice and self-determination as the direction that system improvements would follow, several other agreements have been reached on the particulars involved with that pursuit. However, the Stakeholder Workgroup has not yet reached consensus on two major issues: 1) how to use and/or re-deploy any "unneeded" residential habilitation center resources, and; 2) the role of various government entities in implementing a choice and self-determination approach. These two unresolved issues, as well as a number of additional issues that the Stakeholder Workgroup is currently scheduling for discussion, will continue to be the focus of Stakeholder Workgroup and division activity for the next two years.

In summary, a self-determination approach will provide individuals and their families with more power to choose the services and supports that best suit their individual needs and to select the providers of these services and supports. A self-determination approach will also provide an effective and equitable method of budgeting and allocating resources to meet those needs.

Introduction

This is the second of three reports from the Division of Developmental Disabilities (the division), in response to RCW 71A.12.170 that includes the participation and advice of the Stakeholder Workgroup. The Department of Social and Health Services Secretary Lyle Quasim established this Workgroup in 1997. The three elements in the workgroup's charge were to:

1. develop recommendations on future directions and strategies for service delivery improvement
2. develop an agreement on the direction the department should follow in considering the respective roles of the residential habilitation centers (RHCs) and community support services
3. focus on the resources for people in need of services

These three elements were codified in Title 71A RCW, the statutory section of the law that governs the Division of Developmental Disabilities.

In December 1998, the department delivered the Strategies for the Future Long-Range Plan Phase I Report to the Washington State Legislature. The Phase I Report primarily addressed element 3, focusing on the estimated unmet needs of individuals with developmental disabilities and their families/guardians. The report described and focused on unmet needs as estimated through 2001 in the areas of services and supports, service provider stabilization, and system functions, such as case management. In addition, the report recommended improving the service delivery system by exploring choice and self-determination as a foundation for future services.

The Phase II Report addresses element 1, recommendations on future directions and strategies for service delivery improvement and describes continuing work on element 2, agreement on the direction the department should follow in considering the respective roles of the RHCs and community support services.

The Phase II Report builds a framework for implementing choice and self-determination articulated in Chapters 1 and 2. Chapters 3 and 4 outline proposed activities and long-term strategies.

In preparation for the Phase II Report, the division and the Stakeholder Workgroup convened four workgroups. Over one hundred and twenty people participated, including individuals with developmental disabilities, parents and guardians, service providers, county service administrators, state labor representatives, state management staff, and local and national consultants. Three workgroups reviewed and recommended changes to current service delivery to better support choice and self-determination. One workgroup focused on overall systemic changes needed to develop a choice and self-determination model. Seventy-four recommendations to the division resulted from this stakeholder process and are listed in full in Appendix D.

The ultimate goal of changing to a choice and self-determination service delivery system is

*Over 28,000
individuals are
eligible for DDD
services, a 65%
increase since 1992.*

to provide consumers with an effective array of service and support choices driven by individual need. A number of challenges must first be addressed to move in this direction, including evaluating the potential impact on service availability and cost, public accountability, and system administration. An ongoing task of the Stakeholder Workgroup is to continue studying these challenges and develop recommendations to address them.

The Phase III Report, due in December 2002, will detail what is learned from piloting a choice and self-determination model. It will describe what is needed to implement a choice and self-determination system statewide. Finally, the Phase III report expects to make recommendations on the respective roles of residential habilitation centers and community support services.

Chapter 1

A Framework for Choice and Self-Determination

Focusing on individual choice and self-determination to guide service delivery is a national and international movement. It is the logical result of efforts to build service systems based on the values of inclusion, respect and security. Nearly every state in the United States, as well as many other countries are transforming developmental disabilities service systems from professional and provider driven to individual and family driven. (For more details about choice and self-determination from international, national, and state perspectives, please see Appendix C.)

In Washington, a self-determination approach will provide individuals and their families with more power to choose the services and supports that best suit their individual needs and to select the providers of these services and supports. A self-determination approach will also provide an effective and equitable method of budgeting and allocating resources to meet those needs.

Following are descriptions that describe the types of changes sought.

“Choice is a means by which individuals with developmental disabilities, and their parents/guardians if appropriate, make decisions based upon their values, knowledge, and available resources. The ongoing process includes, but is not limited to, decisions involving life planning, living arrangements, education, career, and leisure activities.”

Self-determination simultaneously promotes greater individual freedom and greater responsibility:

- Individuals with developmental disabilities have expanded freedom to plan their own lives and make life choices.
- Individuals with developmental disabilities have authority or control over their lives, including control over individual budgets, so that needed and preferred supports can be acquired.
- Individuals with developmental disabilities need increased opportunities for community integration.
- Individuals with developmental disabilities take on the responsibility of living in interdependent communities, participating in and contributing to their community.
- Individuals with developmental disabilities assume fiscal responsibility. With growing needs for developmental disabilities services, an emphasis on fiscal responsibility is necessary. Giving people control and choice-making authority over public funds necessitates accountable use of the funds. With participant-driven supports, individuals with developmental disabilities receive the support needed - no more, no less.

A self-determination approach will also provide an effective and equitable method of budgeting and allocating resources to meet individual needs.

Promoting greater freedom and individual control over the resources dedicated to meeting a person's needs:

- Services must be of high quality, provided by qualified service/support individuals or organizations, in a safe and effective manner.
- Services must be delivered within contractual agreements and respectful of personal and civil rights.
- Services must meet all state and federal laws and regulations.
- All individuals with developmental disabilities of working age must be supported to find/maintain employment or, if employment is not a current option, supported to participate in the vital activities of community life.

Chapter 2

Planning and Individual Budgets

A system based on choice and self-determination includes an expanded commitment to individual service planning, seeking out all public, private, and generic services and resources available to individuals and their families/guardians. It does not rely solely on specialized support through DDD. (For more detailed information on planning and individual budgets, see the choice and self-determination section of Appendix D.)

The proposed planning process seeks generic and other “non-public” resources first, followed by department/division resources as needed. Providing skilled planning and assistance in connecting to available community resources is expected to extend the reach of division resources. Once fully implemented, the intent is to make this expanded planning service available to all eligible individuals with developmental disabilities and their families/guardians who want and need it.

Currently, available division services and supports fall into three general categories:

- Individual and family supports
- Employment and day program services
- Residential services

Approximately 80 percent of all persons served are in the first two categories.

Individual and family supports are the most widely used. Most of the people served by the division reside in their family home where supports are provided. The original family support program provided a limited set of respite and other in-home services. In recent years the division has created an alternative program, known as Family Support Opportunities. Each person receives an annual allotment of funds. Individuals and their families have flexibility to choose services and supports they believe will best meet their needs.

A second group of services, employment and day program services, is cost effective in terms of return on investment and benefits to the consumer. Adults with significant developmental disabilities are supported to obtain employment and become typical taxpayers. Washington is nationally recognized as successful in providing access to real jobs, wages, and benefits. People are supported to participate in and contribute to the vital activities of community life if employment is not a current option. Infants and toddlers with developmental disabilities under the age of three and their families are supported with needed educational, therapeutic, and recreational services. Maximum impact on individual development and growth is made in these critical first three years of life.

A third group of services focuses on the residential needs of individuals with developmental disabilities. Consistent with the preferences articulated in current law, most adults are supported to live in a home that they own, rent, or lease. Supports may be provided

The proposed planning process seeks generic and other “non-public” resources first, followed by department and division resources as needed.

around the clock or on a more limited, as needed basis. Other people served by the division live in residences or facilities owned by service providers or by the state. These settings include group homes, adult family homes, and state operated residential habilitation centers. Approximately twenty percent of the division's caseload receives residential services and supports.

With these patterns of service utilization in mind, the division is proposing a two-part resource allocation process. All eligible individuals with development disabilities will receive a standard allocation, similar to the current family support allotment, allowing individuals and their families flexibility to choose the services and supports they need. (The complete list is provided in Appendix D in the Choice and Self-Determination section.).

If the person is between the ages of 0-3 or over age 21, the standard allocation will include added resources for an early intervention or employment service respectively. Individuals who need residential and/or more intensive supports will receive a second allotment to their individual budgets determined by an objective needs assessment process requested by the person or their family/guardian.

Chapter 3

Getting Started - First Steps

The targeted date in the division's strategic plan for completing the move to a choice and self-determination service delivery system statewide is July 1, 2007. The Stakeholders and the division believe that individuals and their families can best describe their needs and determine how their needs may be met. The transition to a choice and self-determination system will enable people to choose the services and supports that best suit their individual needs and have an immediate and forceful impact on quality. Since individuals and families will only use the services they need, this approach will provide an effective and equitable method of budgeting and allocating resources. For the full benefits of a choice and self-determination approach to be realized, however, much still needs to be learned. During the 2001-2003 biennium, the division proposes to focus on testing choice and self-determination components and system assumptions.

Currently in draft form, the implementation plan is organized into three primary activities:

1. Choice and self-determination system components pilot.

The pilot will test assumptions and components from the Stakeholder Workgroup approved choice and self-determination recommendations presented in Appendix D. These include:

- Individual budget allocation
- Person-centered plans
- Personal agents
- Fiscal agents
- Provider certification
- Quality assurance
- Provider stability and service costs
- Pilot evaluation
- Appeal procedures

A pilot project designed by the division and reviewed with the Stakeholder Workgroup would include approximately fifteen percent of the division's current non-high needs caseload. This is considered the optimum sample size for beginning to understand the impacts that self-determination has on consumers, providers, and service costs that could be piloted in one of the division's six regions.

A majority of the people sampled would include individuals currently receiving Family Support Opportunities, Adult Employment and Day Program, and Medicaid Personal

In 2001 through 2003, the division proposes to focus on testing and learning about choice and self-determination components and system assumptions.

Care (children or adult) funding. Some individuals would not be receiving current services and would be phased in during the biennium. While 15 percent is an optimum size to pilot in one region, a smaller pilot is possible and would contribute most of the needed information. The pilot project also includes a crisis reserve fund, information and education, generic community support development, and evaluation components.

Individual budgets for pilot project participants will be based on a “general” allocation of approximately \$6,520 (maximum) per year. The general allocation represents the current spending average for family support, and depending on the person’s age, an amount for early childhood services or adult employment/day program services.

2. Accurate and objective assessment instrument for persons with intensive needs.

The initial pilot project will include only those individuals who can be supported within the general allotment. The division does not currently have access to a standardized assessment instrument that can reliably predict the additional “specialized” resources that may be needed by persons with more intensive needs.

The division plans to test the use of the North Carolina Support Needs Assessment Profile (NC-SNAP) to evaluate the needs of a sample group of individuals currently receiving services. The results will be compared/contrasted against current allocations. The SNAP will then be applied to additional sample groups and contrasted with other needs assessment instruments. Studies of reliability, validity, and “user friendliness” will be conducted to determine if the SNAP can be used as is, or if another instrument or approach should be identified.

An additional “applicability” study will be undertaken once the SNAP or an alternative assessment instrument has been successfully utilized in community settings. The latter study will determine if the same instrument can be successfully used with individuals residing in institutional settings.

3. Residential Individual Budget Portability Pilot.

The division proposes a pilot to test “cost-of-care adjustment” payments and portable resources for individuals who choose to change their shared living arrangements. This pilot is in response to a residential workgroup recommendation outlined in more detail in Appendix D, Section 2.

When a person lives with other roommates in a house where residential services are provided, the funding for each individual’s support is interdependent among all residents of the home (usually 3-4 people with developmental disabilities). If a housemate chooses to move with their support funds from the home, funding for the remaining residents is adversely effected until a new resident moves in or the available supports are adjusted.

This recommendation affects people who share living arrangements with others. It supports the right to choose by making it possible for someone to choose another living arrangement without adversely affecting others.

Chapter 4

Implementation - Stakeholder Recommendations

Next Steps

Chapter 3 described three key recommendations made by the Stakeholder Workgroup necessary to gather more information about how some components of choice and self-determination will work. A total of seventy-four recommendations were made by the four workgroups to implement a system change. These are detailed in Appendix D as described by each of the four workgroups. The department has not had time to thoroughly review all seventy-four recommendations. Consequently, all recommendations have not been approved for action by the department.

The department intends to respond to every recommendation. Some recommendations overlap, some can be addressed immediately within current resources, and others need a more detailed review. For purposes of summarizing in this report, the recommendations are categorized into six groups and examples given for each group.

1. Recommendations that are dependent on receiving new resources. Examples include:

- Choice and self-determination system components pilot
- Service stabilization for individuals who want to change service providers
- Eligible persons offered a choice of RHC or appropriate community residential option
- Enhancement of provider wages
- Resources for people not receiving services, for example family support or transition funding
- Capacity to perform case management activities that are required to maintain a source of federal matching funds for services - a necessary implementation step that is not one of the 74 workgroup recommendations, but is discussed at length in the Phase I Report

2. Recommendations that will be pursued, at least in part, within existing resources and within the division's strategic plan. Examples of some planned activities include:

- Development of a comprehensive quality assurance system.
- Simplifying the current non-facility based residential service system by combining program categories and supporting individuals based on specific support needs.

Some recommendations overlap, some can be addressed immediately within current resources, and others need a more detailed review.

- Increased adult-family home staff training and continuing quality assurance activities.

3. Recommendations that require further work, such as cost estimates and development of implementation strategies and evaluation processes. Examples include:

- Extending Birth-to-Three funding through the summer months to improve a child's transition to school
- Implementing the Pathways to Employment and Alternatives to Employment recommendations
- Increasing out-of-home respite opportunities for families
- Implementing an individual provider rate study

4. Recommendations that are sequential in nature and cannot be pursued until related activities produce results. Examples include:

- Applying an assessment instrument in RHC, State Operated Living Alternatives (SOLA), and other settings. This depends on the initial testing results with people currently in community settings.
- Developing a statewide provider certification system. This depends on the results of the initial pilot.
- Implementing an appeal process relative to assessment of resource needs. This is dependent on the testing and approval of an assessment instrument.

5. Recommendations that affect programs operated by other administrations, other governmental agencies or that require legislation. Examples include:

- Moving the administration of adult-family homes serving only persons with developmental disabilities from Aging and Adult Services Administration to the division
- Transitioning from school to community work or activities beginning at age 14 for all eligible students requires a coordinated effort by the Office of Superintendent of Public Instruction, DDD, and Division of Vocational Rehabilitation
- Extending nurse delegation legislation to include delegation of nursing tasks in family home settings

6. Recommendations that contain issues that need further study by the Stakeholder Workgroup and DDD to reach consensual agreement. Examples of these issues include:

- Role of government relative to individual budgets and choice/self-determination.
- Future role of RHCs and community services, including RHC vacant-bed resources.

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APPENDIXES

Appendix A

Division of Developmental Disabilities Current Service Information

The division provides a broad range of services and supports to over 30,000 eligible clients. These services may be direct or indirect and may occur either in an individual's home or in another setting. The services may be provided by a state employee or through a number of contracted providers.

Vision Statement

People with developmental disabilities and their families are valued citizens of the state of Washington. Washington State public policies will promote individual worth, respect and dignity such that each individual is valued as a contributing member of their community.

Mission Statement

To make a positive difference in the lives of people eligible for the Division of Developmental Disabilities services, through offering quality supports and services that are individual/family driven; stable and flexible; satisfying to the person and their family; and meets individual needs. Supports and services are offered in ways that ensure people have the information to make decisions about their options and provide optimum opportunities for success.

Core Values

- **Individual Worth And Development**
People are served with dignity and respect for individual differences and have the benefits of relationships with friends and families; personal power and choice; personal value and positive recognition by self and others; integration; competence to manage daily activities and pursue personal goals; and health and safety.
- **Continuity And Coordination Of Services**
Emphasis is on a flexible system, which enables people to remain in their own homes and communities whenever possible.
- **Community Participation And Partnership**
Promotes the involvement of consumers, parents, service providers, advocates, local governments, citizens and businesses.
- **Respect For Employees**
Employees are treated as the division's most valuable resource.
- **Services Quality And Performance Accountability**
The division is accountable to the public for effective and prudent use of resources. Regular review, evaluation, and modifications of programs and services are conducted.
- **Non-Discrimination**
The division's policy is to not discriminate on the basis of sex, race, color, religion, national origin, age, or disability in admission and access to services, treatment or employment in its program or activities.

Listing of Statutory Authority References

Washington State Constitution- Article XIII, Section 1 - Requires the state to foster and support "educa-

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tional, reformatory, and penal institutions that are for the benefit of youth who are blind and deaf or otherwise disabled; for persons who are mentally ill or developmentally disabled; and other institutions as the public good may require

Title 71A RCW - passed by the 1998 legislature, this chapter reorganized and clarified laws regarding the provision of service to persons with developmental disabilities. The key sections are:

RCW 71A.10.020- Definitions of developmental disabilities

RCW 71A.10.015- Service obligations

RCW 71A.12.010- Authority to develop and coordinate state services

RCW 71A.12.030- Statutory duties and responsibilities

RCW 71A.12.020- Service Requirements

RCW 71A.10.020(4)- Habilitative services defined

RCW 71A.12.040- Authorized services listed

Chapter 71A.14 RCW - Local service options outlined

RCW 71A.14.080- Local authority defined

RCW 71A.16.010- Service eligibility

Chapter 71A.18 RCW - Special conditions for services

Chapter 71A.20 RCW - Residential Habilitation Center operations

RCW 71A.22.010 -Authorizes training centers and homes

RCW- 74.09.120 - Authorizes the state to purchase services and care in institutions for the mentally retarded.

RCW- 74.09.520 - Authorizes the Department of Social and Health Services to provide Medicaid Personal Care.

Executive Order 92-10 - Designates the Department of Social and Health Services as the lead agency to implement a comprehensive and coordinated state-wide system of early intervention services for eligible infants and toddlers with disabilities and support for the State Interagency Coordinator Council (RCW 70.195.30) (Public Law 105-17) (34 CFR, Part 303).

Program Descriptions

Case and Resource Management – The initial service provided by the division is eligibility determination. A case manager is assigned to assess the needs of clients and families and link these needs to available services. Additional responsibilities of case managers include the development of individual service plans, authorizing payments of publicly funded services, arranging for service delivery, providing information about available services, referring persons to other sources of support, and crisis intervention.

Community Residential Services – These services are provided to persons who require assistance with daily living. The division contracts for these services with organizations or individuals who provide varying levels of assistance. Services include both facility based and non-facility based programs.

- **Facility Based Programs** – In these residential programs the provider owns the facility. Room and board expenses are included in the rate paid by the division. They include:
 - **Group Homes**, licensed by Aging and Adult Services Administration (AASA) either as boarding homes or as adult family homes. Each facility serves from 3 to 20 adults and provides on-site supervision during the hours clients are in the facility. Other services include training, money management, transportation, and personal care supports.
 - **Intermediate Care Facilities for the Mentally Retarded (ICF/MR's)**, licensed by AASA as boarding homes or nursing homes and house from 6 to 32 adults. ICF/MRs offer more intensive nursing and therapy services, and work-related assistance. These facilities must meet federal standards and receive matching funds through Title XIX, Medicaid.

- **Non-Facility Based Programs** – These programs provide support and training to persons living in their own homes in the community that they rent or own. Clients pay for their own rent, food, and other personal expenses. These programs include:
 - **Supportive Living**, including alternative living and tenant support, provides a range of direct staff training and support from one to an approximately 70-hours per month on a flexible schedule according to the individual's needs; and Intensive Tenant Support with training and supports ranging from 3-4 hours of direct staff support per day to 24 hours of one-to-one support per day.
 - **State Operated Living Alternatives (SOLA)** provide Intensive Tenant Support Services as described above, but are staffed by state employees.
- **Other DSHS Facilities** – In addition to the residential programs directly operated or contracted by the division, many clients receive services in settings funded through or operated by other DSHS programs. These include:
 - **Adult Family Homes**, which house up to six persons who cannot live alone but do not require skilled nursing care;
 - **Nursing Facilities**, which provide an extensive array of services for persons requiring daily nursing care, assistance with medication, eating, dressing, or other personal needs;
 - **Adult Residential Care Facilities**, provide 24-hour supervision and assistance with activities of daily living within a licensed boarding facility;
 - **Foster Care**, provides out-of-home contracted residential care for children who cannot live with their parents.

Employment and Day Programs – Approximately one-third of the persons enrolled by the division are involved in a day program. These programs are paid by the division through contracts with counties. The counties select and contract with service providers. The purpose of day programming is to provide employment-related support and vocational opportunities to individuals to help them integrate into the community. These services include:

- **Employment Services** – The division contracts for three types of employment programs, including:
 - **Individual Employment**, assists individuals with finding and keeping jobs in private businesses. These programs match participant interests and skills to available community jobs, provide extensive on-the-job training, offer training to supervisors and co-workers on working with clients, and provide ongoing support;
 - **Group Supported Employment**, enables individuals to work in community settings in supervised groups of no more than eight person;
 - **Specialized Industries**, provide pre-vocational program training in a sheltered setting.
- **Community Access Services** – These programs emphasize the development of social, communication, and leisure skills for individuals whose age or disability limits their participation in employment. Persons gain access to community activities through special assistance, advocacy, and education.
- **Child Development Services** – These services include therapy, education, family counseling, and training, and are provided to children until age three, when they become eligible for services through public schools. These services are enhanced and monitored through the Infant and Toddler Early Intervention Program, transferred to the division in the 1995-97 budget.

Infant and Toddler Early Intervention Program provides services through federal funds to enhance and coordinate existing early intervention services and assure federal service standards are followed. These

services include family resources coordination, therapies, and family training and counseling for infants and toddlers, birth to three, with developmental delays or disabilities, and their families. Services are family centered, to occur in natural settings, foster collaborative partnerships and are built upon mutual respect and family options relative to the child and families culture, strengths, resources and concerns.

Family Support Services – This program provides families with the supports necessary to keep individuals at home or with relatives. These services include:

- **Respite Care**, provides in or out of home care in order to provide short-term relief to the family;
- **Attendant Care**, provides in-home care or personal care services to families who require assistance with an individual with major physical or behavioral needs; and,
- **Transportation**, provides assistance to persons needing transportation to appointments or day programs.

Professional Support Services – The division funds a variety of professional services that enhance the functional and adaptive skills of individuals. These services include:

- **Counseling and Therapeutic Services**, include psychological services, professional evaluations required by the courts as well as other therapeutic services;
- **Supplemental Community Support**, provides professional services to individuals living apart from their families.

Medicaid Personal Care – This is a federally matched entitlement program that provides assistance with the activities of daily living to individuals living in their own homes, adult family homes, or congregate care facilities.

Foster Care Voluntary Placement Program – Children with developmental disabilities who are under 18 years of age may, in certain circumstances, be eligible for out-of-home placement in licensed foster care settings and support services. The voluntary placement of a child in out-of-home setting must be by mutual agreement between the family and DDD. The birth / adoptive parents retain custody of the child. The foster placement, arranged for a short period of time, is viewed as a positive support to the family and child or youth. The division views the arrangement as appropriate to the needs of the child, as shared parenting with foster care providers and as a support to the family. In each of the six DDD regions, there are DDD social workers and a voluntary placement supervisor that manage requests for these services.

Residential Habilitation Centers – The Residential Habilitation Centers (RHCs) are state-operated residential facilities that provide a comprehensive array of clinical and support services within a 24-hour setting and offer short-term admission / respite services for eligible clients. The RHCs are federally certified facilities and receive matching funds through Title XIX, Medicaid. Services are provided based upon Individual Habilitation Plans and typically include habilitation, training, adult education, an array of specialized therapies, nursing, medical, and dental care, and recreation services. There are five RHCs located state-wide, including:

- **Fircrest School**, located in Seattle, serving 283 individuals and certified in part as a nursing facility with the remainder certified as an intermediate Care Facility for the Mentally Retarded (ICF/MR);
- **Lakeland Village**, located in Medical Lake, serving 258 persons and certified partially as a Nursing Facility and an ICF/MR;
- **Yakima Valley School**, located in Selah, serving 107 individuals and certified entirely as a nursing care facility;
- **Rainier School**, located in Buckley, serves 426 persons and certified entirely as an ICF/MR;
- **Frances Haddon Morgan Center**, located in Bremerton, serving 54 persons with autism and certified entirely as an ICF/MR.

Special Population Program Support

- **Community Protection Program:** The DDD Community Protection Program provides intensive 24-hour supervision for individuals who have been identified as being a danger to their community due to the crimes they have committed. This program is an opportunity for participants to live successfully in the community and continue to remain out of prison or other justice system settings. Environmental and programmatic safeguards are in place to protect neighbors and community members, to the extent possible, from behaviors that endanger people or property and/or interfere with the rights of others. This structured, specialized environment gives participants the opportunity to make positive choices to resolve or contain the behaviors that require intensive intervention and supervision.
- **Developmental Disabilities/Mental Health Collaborative Plan:** This plan includes a variety of strategies and partnerships between mental health staff, developmental disabilities staff and community-based organizations and programs aimed at diverting individuals with developmental disabilities from psychiatric hospitalization. It provides for an increase in services such as crisis intervention and prevention, behavioral support and technical assistance, capacity, residential outplacement capacity and medication evaluation and monitoring.

DDD's Website: <http://www.wa.gov/dshs/ddd> **for contact information.**

*State public policies
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individual worth,
respect and dignity
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as a contributing
member of their
community.*

Appendix B

Stakeholder Workgroup Background

In June 1997, Department of Social and Health Services (DSHS) Secretary Lyle Quasim established the Division of Developmental Disabilities Strategies for the Future Stakeholder Workgroup to: “develop recommendations on future directions and strategies for service delivery improvement, resulting in an agreement on the directions the department should follow in considering the respective roles of the residential habilitation centers (RHCs) and community support services, including a focus on the resources for people in need of services.”

The Stakeholders and the Division of Developmental Disabilities (the division) decided to employ a mediation process that supported all members to articulate their concerns, perspectives, preferences, and interests, using a method referred to as interest-based bargaining. All issues associated with any particular proposal had to be resolved to an acceptable degree for each and every member in order for the proposal to advance. This method offered an effective process for building durable solutions and member satisfaction.

In December 1997, the Stakeholder Workgroup developed a strategic plan outline, referred to as the Agreement in Principle. The Agreement established the values, principles, and methods that the Stakeholders and the division were adopting in order to adequately fund and improve access to needed services and supports. Specifically, the Agreement employed a “choice and self-determination” model for restructuring services and supports to give individuals with developmental disabilities and their families/guardians substantial control over the state resources dedicated to meeting their needs. The Agreement also articulated processes for data gathering/analysis, long-range planning, and mediation use in determining how to restructure services and supports.

In March 1998, Substitute Senate Bill 6751 (an act relating to stabilizing long-term care for persons with developmental disabilities living in the community and in residential habilitation centers) was passed and codified in Title 71A RCW, the chapter of state law that governs the division. The Strategies for the Future Stakeholder Workgroup was established in law to participate with the division in making recommendations on future direction and strategies for service delivery.

In December 1998, the division, with the participation of the Stakeholder Workgroup, submitted the Strategies for the Future Long-Range Plan Phase I Report to the Washington State Legislature. The Phase I Report attempted to estimate the current and projected unmet service and support needs of individuals and their families/guardians, including a prioritized, multi-biennial funding plan. The Phase I Report also described the approach that the Stakeholders and the division would take to restructure the service delivery system using a choice and self-determination model.

In February 1999, four workgroups were formed to develop recommendations in the areas of: Choice, Residential Supports, Employment and Day Program Supports, and Individual and Family Supports. Each workgroup included individuals with developmental disabilities (also referred to as self-advocates), Stakeholder, provider, labor, and division management participation. All workgroup members participated in a “kick-off” conference that included national experts, researchers, and others from several states who were designing or implementing choice and self-determination service systems. In total, over 120 people contributed their perspectives and skills in proposing a better system of services and supports.

The complete Stakeholder Workgroup recommendations to the division are preserved in the Stakeholder Workgroup meeting minutes and attachments. The four workgroups’ 74 recommendations are also provided in detail in Appendix D.

Appendix C

National And State Self-Determination Movement

Section 1 - National Self-Determination Movement

The self-determination movement should not be considered a new phenomenon or a fad. Rather, it is firmly rooted in the civil rights movement, a logical extension that includes people with all kinds of disabilities under the umbrella of the rights and expectations experienced by all other citizens. Self-determination is built on civil values that include freedom, support, authority, and responsibility. While it may be accurate to view self-determination's first emergence through the voices and actions of people with physical disabilities, its spreading influence is being carried throughout the country and at all levels of government by people with cognitive disabilities, families, guardians, advocates, and many others.

Self-determination has been around for nearly twenty-five years. Self-advocates and their families in British Columbia pressed the Provincial Government to develop a service system where families gained substantial control over the resources that were dedicated to the care and well being of their family members with intellectual disabilities. In the United States, nearly every state, major governmental funding source, and policy/service consulting organization have devoted time and energy to address the fundamental "civil" deficits identified by self-advocates and family spokespersons. It is a move from a service delivery system viewed as being "professional and provider driven," to a service that is fundamentally "individual and family driven."

Several new forums and organizations have formed as a result of the growing interest and civil rights concerns associated with the self-determination movement. The Robert Wood Johnson Foundation has developed The National Program Office on Self-Determination under the directorship of Charles Moseley, Ed. D., through The Institute on Disability at the University of New Hampshire (<http://www.self-determination.org>). In September 2000, the Center for Self-Determination, under the direction of Tom Nerney, Executive Director in Wayne, Michigan, produced its first newsletter and web site (<http://www.self-determination.com>).

Most recently, the "First International Conference on Self-Determination & Individualized Funding," sponsored by dozens of organizations throughout the world, was held in Seattle, Washington and attended by 1,500 people. Hundreds of self-advocates, family members, providers, policy makers, and concerned citizens from Washington attended. The Division of Developmental Disabilities sponsored attendance for members of the division's state advisory committee and the Stakeholder Workgroup.

The conference's primary focus was on the use of "individualized budgets." These budgets are available as a sort of governmental service "line of credit" that is directed toward the payment of needed supports and services at the discretion of self-advocates and their families/guardians. This fundamental shift of power and control is the civil rights issue that is at stake.

Section 2 - Self-Determination In Washington State

Several examples of self-determination currently exist in Washington. A local chapter of the national "Self Advocates Becoming Empowered" has been active since the early 1990's. It has developed local forums and opportunities for self-advocates to communicate what they want, need, and expect from their communities and government service delivery systems. Likewise, the Washington State Developmental Disabilities Council has been actively researching and developing recommendations for moving into a self-determination system of services and supports. These recommendations are provided in their most recent three-year planning document and are reflected in their funding support of demonstration projects. (<http://www.ddc.wa.gov>)

Self determination is a move from a service delivery system viewed as being "professional and provider driven," to a service that is fundamentally "individual and family driven."

In 1996, the division launched an alternative method for delivering Family Support (FS) services. The new program, Family Support Opportunities (FSO), was designed to offer much greater flexibility and family control over the use of FSO. The trade-off was that the annual budget amount available was about a third of the annual average dollars available through the more rigid FS program. A recent evaluation of the FSO program showed that seventy-nine percent of the families surveyed were satisfied with their role in defining what they needed from the program. The FSO program used a broad service menu approach and “community guides” to help families connect to needed community services and supports.

The University of Washington’s Center for Disability Policy and Research published an update of the **Catalogue of Innovative Projects** that described 101 projects in Washington aimed at providing services or supports to self advocates and their families/communities. Titled “1997-1998 Innovative Projects” and sponsored by the division, the publication described employment/day services and supports, developing friendships and relationships, family support, and community development programs and efforts. Included in the publication were “Composing a Life” projects in Spokane and Island Counties, sponsored in part with funds from the Robert Wood Johnson Foundation. One of the five major objectives of “Composing a Life” was to increase self-determination and decision-making by self-advocates and their families/guardians. The Spokane project laid additional groundwork around managing individual budgets and budget “portability” for adults using employment/day services. Several counties have moved to an individual budget or allocation approach that encourages individuals to “shop” with their dollars to achieve the best employment and day program service outcomes available.

In March 1999, county coordinators for developmental disability services developed a compilation of community capacity building and individual/family centered projects, activities, and innovations. The compilation is organized into sections on choice, employment and day programs, residential supports, individual and family supports, and community capacity and other activities. Many of these contain choice and self-determination elements. Person-centered planning projects for unserved people have been underway since 1996. Choice and portability of funding for employment/day services exist in several counties, along with several forms of family grants and service brokering.

The Washington Initiative for Supported Employment has been involved with several county projects designed to increase self-determination since 1996, including: Brokerage and Family Empowerment projects in King and Snohomish Counties; Family Grant projects in Clark and Pierce Counties; and Rural Family Grant/DDC New Pathways to Employment projects in Clallam, Skamania, Grays Harbor, and Grant Counties, along with the Prosser School District, and the Yakama Indian Nation.

Current law, directs the division to offer a choice of services to some people needing specialized services (“intermediate care facility for the mentally retarded, (ICF/MR) services,” also referred to as institutional or “RHC-level of care” services). Appropriations were provided that allowed twenty-three individuals and their parents/guardians to review and choose the residential setting that they thought would best suit their needs. The department is seeking funding in the 2001-2003 operating budget to continue to offer a similar choice of services.

Appendix D

Summary of Recommendations as Submitted by the Four Stakeholder Workgroups

Over one hundred and twenty people participated in four workgroups convened by the division in support of the Stakeholder Workgroup planning process. Each workgroup was given a goal statement, as a result of the work presented in the Phase I Report, to make recommendations back to the Stakeholder Workgroup and subsequently to the division. Three workgroups, Residential, Employment and Day Programs and Individual and Family Supports, reviewed and recommended changes to current service delivery in support of individual choice and self-determination. One workgroup, Choice, focused on overall systemic changes needed to develop a model for individual choice and self-determination. The recommendations as presented to the Stakeholder Workgroup by each workgroup are described in this appendix.

Section 1 – Choice And Self-Determination Workgroup Recommendations

“The Division of Developmental Disabilities will restructure system administration and management to support an individual/family centered approach, with an emphasis on quality, access, responsiveness, efficient utilization of resources, and accountability.” (Phase I Report, page 28)

The beginning point was establishing a vision statement and core values. The vision for the future is one in which individuals and their families/guardians are valued citizens of Washington State. That will only happen when the core values of the division promote:

- the worth of each individual and the supports to help them develop their potential
- a continuity and coordination of those supports in such a way that the individual can rely on them
- excellent quality of those supports and responsible performance of the supports that are offered
- community participation and partnership to a much greater degree than is presently achieved

Working definitions were needed for choice and self-determination, as well as general working assumptions that would help communicate the focus and framework for developing and evaluating “self-determination” system restructuring recommendations.

“**Choice** is a means by which individuals with developmental disabilities, and their parents/guardians if appropriate, make decisions based upon their values, knowledge, and available resources. The ongoing process includes, but is not limited to, decisions involving life planning, living arrangements, education, career, and leisure activities.

“**Self-determination** is a human right and value that acknowledges and supports a lifelong process of pursuing learning about oneself, one’s needs and wants, and the pursuit of one’s own goals.

“Overall, the idea is to assure that individuals with developmental disabilities are free to live their lives as they want and that they receive the supports needed to do so. Of course, as with any other citizen, limits on individual preferences are imposed by a variety of factors, such as civil law or one’s personal budget.”

Five principles were identified to guide much of the effort surrounding self-determination:

1. Individuals with developmental disabilities have the freedom to plan their own lives and make life choices.
2. Individuals with developmental disabilities have authority or control over their own lives, including control over resources, so that needed and preferred supports can be acquired.

Choice is a means by which individuals with developmental disabilities, and their parents or guardians if appropriate, make decisions based upon their values, knowledge, and available resources.

3. Individuals with developmental disabilities have access to the support networks they need and the opportunity for increased community integration.
4. Individuals with developmental disabilities take on the responsibility of living in interdependent communities, participating in and contributing to their community.
5. Individuals with developmental disabilities assume fiscal responsibility, which is unequivocally important. With growing waiting lists for developmental disability services and pressure to contain Medicaid spending, an emphasis on fiscal responsibility is necessary. Giving individuals with developmental disabilities control and choice-making authority over public funds necessitates accountable use of the funds. In participant-driven supports, individuals with developmental disabilities receive the support needed - no more, no less.

The next step was to establish that all supports and services will be in accord with federal and state law, including:

- **Title 71A RCW** - section of state law that provides authority and direction to the division for providing services to individuals with developmental disabilities and their families/guardians
- **Title II of the Americans with Disabilities Act (ADA)** - section of federal law that provides certain accessibility, discrimination, and civil rights protections
- **Developmental Disabilities Assistance and Bill of Rights Act** - federal law that establishes state Developmental Disabilities Councils, Protection and Advocacy Systems, and University Affiliated Programs; and directs that individuals and their families/guardians are participants in the design of needed services and individualized supports/personal assistance and promotes self-determination, independence, productivity, integration and inclusion

Nine recommendations for moving to a choice and self-determination system:

Scope of Change

- The system applies to all persons receiving or eligible to receive public resources. Appropriate and cost effective utilization of resources is intended to yield equitable opportunities for those unserved and underserved to gain access to needed services.
- The system applies to all persons in all settings, i.e. is inclusive of community and residential habilitation center service/support settings.
- Special care and attention is needed in evaluating how to address birth-to-three, voluntary placement (foster care), and community protection services in the new service delivery system.
- Full implementation is expected by 2007.

Information Dissemination and Education

For services and supports to be delivered in a self-determination environment, information and education must be supported by the state, regions, and at the county/community level. Resources should be set aside to enhance and support the division's partnership with community organizations. Improving the capacity of individuals and their families/guardians to support one another is essential to effective resource utilization. A consistent, basic information packet should be developed for statewide use. In addition, a strong individual and family/guardian directed education component should be locally available.

Resource Allocation

At the heart of the choice and self-determination movement are "individual budgets." An individual budget provides individuals and their families/guardians the maximum opportunity to control or

direct the essential components of the services and supports they receive. Individuals and their families/guardians will be able to say what they need (the services and support required); who will provide those services and supports (the choice of providers); and manage the budget to make the plan a reality through prioritization (power and control).

The Individual Planning Process (IPP), sometimes referred to as a person-centered plan, begins with consumer choice around planning processes and activities. The person-centered plan is distinct from the resource plan initiated with the case manager when program eligibility is established. The person-centered plan focuses first on non-DDD resources that are available to assist the individual in meeting their needs. Examples include accessing local community leisure opportunities, participating in neighborhood or citywide job fairs, or using other public assistance to help fund vocational training. In the plan, the individual, and their family/guardian if appropriate, will be assisted (as necessary) to design and prioritize their needs and match those needs with resources. A state case/resource manager will authorize specialized services. The personal agent or case manager would also be able to assist the person and their family by linking them with potential service/support providers.

In order to utilize an individual budget system, there needs to be some method for allocating available resources to individuals and their families/guardians. The equitable allocation of resources is a paramount system value. A number of assessment instruments were investigated to determine if an assessment method currently existed that could be useful here in Washington. The Stakeholder Workgroup approved testing of the North Carolina Support Needs Assessment Profile (SNAP) to determine if it could be used for resource allocation purposes (as currently developed or with additional modifications). Testing will include an evaluation of the instrument's validity, reliability, and family-friendly characteristics.

The cost and potential privacy invasion of an intensive assessment process could easily invalidate its use. Based upon the service/support needs assessment data from the Phase I Report, it appears that the majority of people on the division's caseload can be adequately supported within a fairly predictable general allocation. Everyone would be provided the general allotment, similar to the amount currently associated with the Family Support Opportunities program. In addition, individuals under age three and above age 20 would also receive a second amount similar to the amount currently associated with the employment and day programs. For the small percentage of individuals who cannot be adequately supported by the general allocation, a specialized allocation can be requested. The assessment instrument/process would determine the fair and equitable additional amount needed to meet the needs identified in the individual's support plan as approved by case management. All funds allocated to the individual would be available as a single individual budget. Periodic reassessments and reassessment requests (including crisis and urgent situations) would be available to ensure that the changing needs of individuals are planned for and supported.

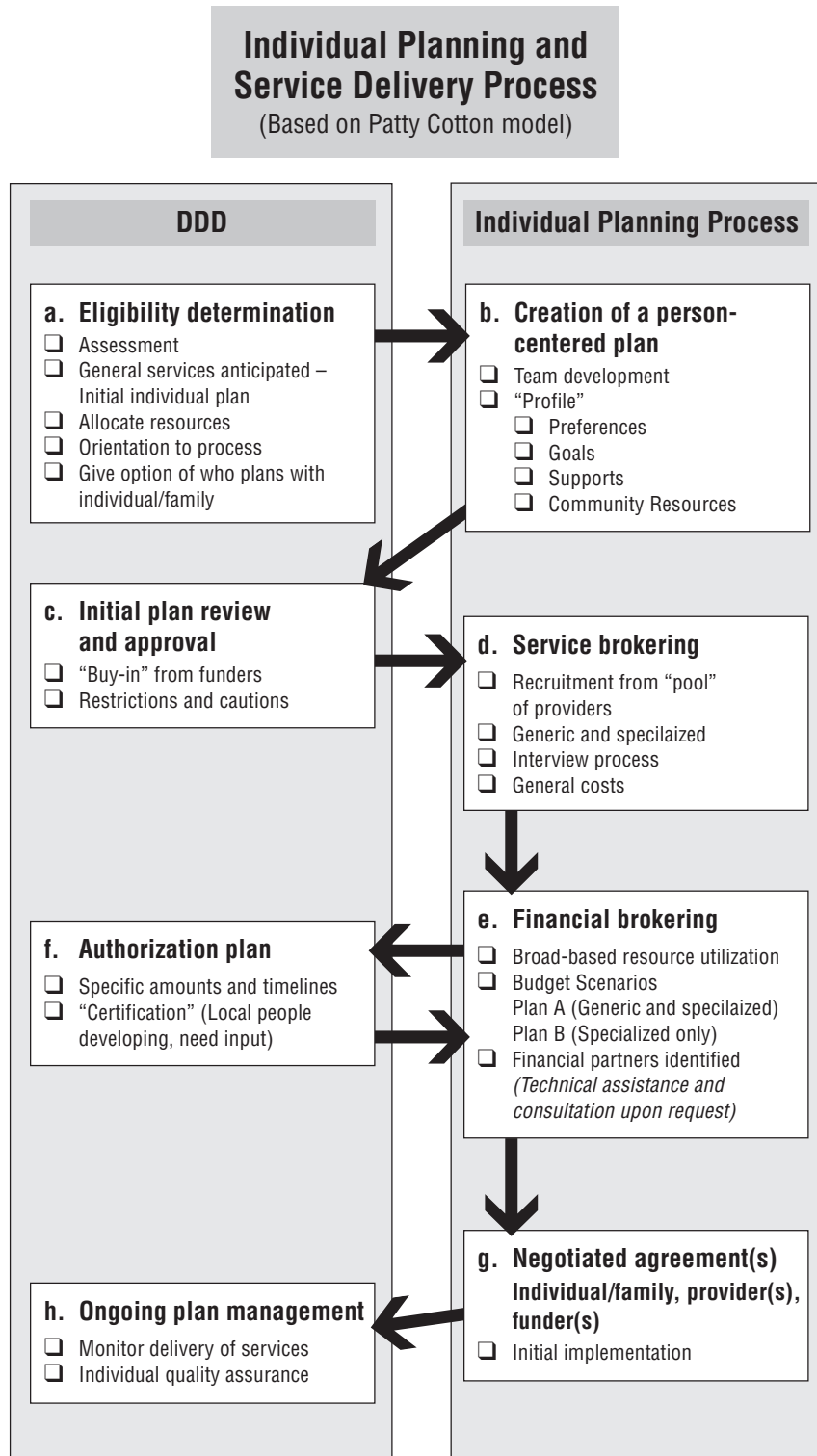
The specialized assessment process must be deployed with an adequate safety net. An appeal process will be instituted so that changes in funding availability for individuals currently receiving community-based services are protected from changes that they may not fully agree with. Once experience using the specialized assessment tool is gained in community settings, the Stakeholder Workgroup and the division will use an applicability study and their consensus process to determine if the assessment tool can/should be used with individuals currently residing in residential habilitation center (RHC) and state-operated living alternative (SOLA) settings.

In summary, choice and self-determination is the driving force in the system restructuring process, using individual budgets as the means to accomplish this goal. Individuals and their families/guardians are free to choose if they want to manage more of their personal services and supports or be assisted by someone. If they choose to take more control, supports are provided to help them along the way. If they believe that the general funding committed to them is not enough, they may request an assessment of their needs and a determination of whether the resources allocated are adequate to meet those needs.

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own goals.*

Individual Planning Process (IPP)

A new individual planning process (IPP) was identified with the help of a national consultant, Patty Cotton. This process identifies system roles and the roles of the individual differently than is currently practiced in Washington State. Table 1 on page 6 of Appendix D provides the outline that was developed, distinguishing DDD roles from “person-centered” individual planning roles:



An individual planning process would maximize the use of natural, or community resources, to allow the individual and their family/guardian to be as much a part of their community as possible. If requested, the individual planning process would identify how to assist the family to connect to all available resources. Division funds would be used only when other resources are not available.

The plans will be required to address age appropriate goals, such as early intervention strategies for children age birth to three, employment or alternative goals for working age adults, and retirement planning for senior adults. All plans will also address expected benefits, including health and safety, personal power and choice, relationships with family and friends, status and respect, integration opportunities in typical community activities, and competence including skills and abilities that enable the person to have greater control of his/her life.

Essential to the entire process is identifying the person who will assist the individual and family in planning, evaluating and finding needed services and supports. The individual and their family/guardian, if appropriate, will decide what planning help they need, if any, and from whom. Alternatively, they may decide not to seek additional help and prepare the plan themselves.

Menu of Services and Supports

In developing a menu of services and supports, it was important not to limit choices but to allow for the broadest array of choices while still honoring the need the individual to be accountable for their choices. The net result is that individual budgets can be used in different ways to support individual needs. The boundaries for what the individual budget can pay for will ultimately be determined when the case manager authorizes the plan.

The individual's resource allocation is intended to meet each person's specialized needs and to promote, to the maximum extent possible, the person's inclusion in typical activities and events in his/her community. All the components of the menu below fully embrace the concept of "informed choice" and self-determination. The funds to provide these services are to be used to complement, not substitute for, other public or private resources available to the person or family.

– Individual budgets may include the following:

- Education/information/training opportunities to gain knowledge and skills for increasing personal and social independence.
- Living arrangements that include personal supports purchased from certified providers. This includes, but is not limited to: direct personal care, personal skill building, independent living tasks, financial management, medical monitoring/appointments, meal preparation, shopping, home maintenance, community access/integration, and opportunities to develop relationships and participate in activities of choice. Living expenses, which include unusual or extraordinary disability related shelter expenses, may also be provided.
- Employment supports and tuition to help people move towards career employment goals. This can include job development, job coaching, employment participation, computer technology, co-worker support, and supervisory support. These supports must be purchased through certified providers.
- Paying for the expenses involved in typical community activities such as senior programs, volunteering, contributing to the community, club membership, recreation, etc.
- Birth to three/early intervention services, that are multi-disciplinary services including early identification, eligibility determination, and timely referral to supports/service options, may be purchased through certified providers.
- Assistive technology and supports required to gain or maintain independence such as

specialized medical equipment and supplies to include devices, controls, or appliances, which enable individuals to increase their abilities to perform acts of daily living or to perceive, control, or communicate in the environment in which they live.

- Respite care, including community activities providing respite, attendant care or nursing care.
- Family training - parenting classes and supports such as disability related support groups.
- Specialized equipment and supplies purchased, rented, or refurbished not covered by other resources, including Medicaid. Diapers may be approved only for those three years of age and older.
- Developmental equipment, supplies, and materials that are appropriate and needed for growth and development and are not covered by Medicaid or other funding sources.
- Environmental modifications and home modifications made necessary because of a family member's disability, including repairs to home damage caused by the individual.
- Therapies such as occupational therapy, physical therapy, communication therapy, behavior management, visual and auditory services, or counseling needed by individuals with developmental disabilities but not covered by another resource such as public schools or child development services funding.
- Medical/dental services not covered by another resource. These services may include the payment of insurance premiums and deductibles but are limited to the portion of the premium or deduction that applies to the individual.
- Nursing services, not covered by another resource, that cannot be provided by an unlicensed care giver but can only be rendered by a registered or licensed practical nurse. Examples of such services are ventilation, catheterization, and insulin shots.
- Special foods or formulas necessary because of the individual's disability.
- Parent/family counseling for grief and loss issues, behavior management training, or genetic counseling services.
- Specialized clothing adapted to accommodate physical disabilities, specialized footwear, or clothing modified for excessive wear.
- Specialized utility costs including extraordinary utility costs resulting from the individual's disability or medical condition.
- Transportation costs, if another resource is not available, including gas, ferry or transit costs, so an individual can receive essential services and maintain appointments; per diem costs may be reimbursed for medical appointments.
- Other services approved by the Division of Developmental Disabilities regional administrator or designee, according to established department guidelines.

– Individual Budgets MAY NOT include the following:

- Illegal purposes
- Reimbursement to providers who do not meet contract requirements

Role of Government - Draft of Concepts Under Consideration

The respective roles and relationships of government are not yet finalized but will emerge as a result of piloting activities and further consensus building. The concepts currently under discussion include:

- Personal agent services administered by counties.
- Allocations made to individual accounts, eventually held by (non-governmental) third party entities.
- Generic community development and specific funding for counties to expand current efforts.
- Resource development for individuals and their families/guardians, focusing first on generic development of resources and then on DDD resources; county/state personnel will focus on development of essential provider capacity.
- Quality assurance pursued at all levels of state government, including provider networks. Development of standards and compliance functions will remain as a state managed function.
- Initial provider certification will be a state responsibility; counties and the state will establish a partnership to address ongoing certification, monitoring, technical assistance, evaluation, etc.
- Information and education will be a shared county/state/region responsibility for system information. Local information and education will primarily be a county responsibility.

Community Development

Community development strategies in the restructured system will proceed within the conceptual framework established in the county guidelines (available on the division's web site at <http://www.wa.gov/dshs/ddd>) and current division policy. The Guidelines establish the values and expected benefits for individuals and their families/guardians associated with all county administered services. The following recommendations are made to strengthen community development activities:

- Sufficient resources will be available to counties for full implementation of the County Guidelines.
- Funding will be provided for competitive county grants to local communities to increase the participation of individuals in community life, with a priority for rural areas.
- A statewide voluntary oversight committee will be established to document and evaluate current activities and progress on community development and to share successful models.
- Technical assistance will be available to counties.

Quality Assurance

Quality assurance recommendations were developed with input from all four workgroups:

Current system:

- Immediate implementation of a coordinated system of quality assurance activities for people who use individual providers for services and supports.
- The Quality Assurance subgroup will act as the advisory group to the new pilot project on quality assurance in Region 5.
- DDD will prepare a strategic quality assurance plan for implementing quality assurance procedures for all programs, services, and system functions.
- An external ombudsman function should be available for problem resolution support to individuals and their families/guardians.

Future system:

- The assessment, monitoring, and evaluation of all new choice and self-determination system functions should be an ongoing activity.

The Stakeholders recommend collapsing four service categories for individuals living in their own homes into a single flexible “Supported Living” category.

Provider Stability

Provider stability was primarily viewed as service stability. Choices are limited if quality service providers cannot be attracted and maintained. Provider stability issues are prevalent in all areas of division services and supports. Two very strong considerations emerged:

- Provider stability is particularly vulnerable during system restructuring as new ideas are tested and implemented.
- Without a vital provider marketplace that attracts and retains competent, competitive providers, self-determination is not likely to be realized in any meaningful way.

Providers offered suggestions for remaining stable during transition. Some of their suggestions included cost of care adjustments, training, technical assistance and careful consideration of the impact of each change. It was determined that all pilots and system changes will be evaluated in terms of their impact on provider and service stability to ensure that there will be choices still available for people during and after system restructuring.

Section 2 – Residential Supports Workgroup Recommendations

“The Division of Developmental Disabilities will design and maintain an effective system of residential supports and services that provides a full range of service options based on assessed needs, emphasizing choice and efficient resource utilization.” (Phase I Report, page 29)

Five areas of concern were identified and recommendations developed:

Combining program categories for individuals living in their own homes.

Currently there are four service categories for individuals living in their own homes. These services overlap in terms of the range of hours that in-home supports are available:

- Tenant Support: provides a limited amount of hours of support
- Intensive Tenant Support: provides twenty-four hour support
- Supported Living: provides even fewer hours of support
- Alternative Living: covers a few hours of support per month

The Stakeholders recommend collapsing these categories into a single flexible “Supported Living” category. Services and supports will include instruction and support by certified agencies for individuals who live in homes that they own or rent/lease. Persons needing “Supported Living” status will pay for their own rent/lease/mortgage, utilities, food, etc., using their personal financial resources. “Supported Living” levels of supports and service will range from only a few hours a month to twenty-four hour intensive staff support depending upon the needs of the individual.

Service stabilization for individuals living in their own homes who change their service providers.

When a person lives with other roommates in a house where residential services are provided, the funding is interdependent for all residents of the home (usually 3-4 people with developmental disabilities). If a housemate chooses to move from the home, funding for the remaining residents is adversely effected until a new resident moves in or the available supports are adjusted.

This two-phase recommendation affects people who share living arrangements with others. It supports the right to choose by making it possible for someone to choose another living arrangement without adversely affecting others.

- During the first phase, effective July 1, 2001, the division will continue to direct the market. When one household member chooses to move (taking their funding with them to a new residence), the division will be responsible to make a cost-of-care adjustment payment to the residential provider. This is intended to stabilize the services of remaining individuals (whose support arrangement is adversely effected by a housemate's departure) for up to six months (three months plus up to three additional months on a month-to-month basis, or until the household opening is filled, whichever occurs first). During this six-month period, the division will seek to match a person seeking similar supports with the available residential opportunity, using a support arrangement description generated by the provider agency. Once six months has lapsed and another individual has not chosen the support arrangement with the other individuals supported by the provider, a new support plan will be developed with the affected parties. These cost-of-care adjustments are intended to remove barriers which prevent movement into an individual budget, market-driven service delivery system.
- In the second phase, once the new system is implemented, individuals will direct the market with their service purchasing choices as they will have control over their budgets. If an individual does not choose to remain with a provider, that provider may request a cost-of-care adjustment under the same conditions as outlined above, in order to protect the service/support arrangements of the remaining housemates for up to six months.

Other procedures and activities recommended by the Stakeholder Workgroup to move to a choice/market-driven system include:

- Development of a web site to improve individuals and their families/guardians awareness of support opportunities that match their support needs
- Education/information available to individuals and their families/guardians to increase awareness of support “interdependence” issues, service cost expectations, and agency qualifications and performance capabilities to help them make the best use of their resources; and
- For service agencies clear, uniform certification / qualification / performance expectations, funding consistent with service level expectations, and technical assistance support.
- The State Operated Living Alternatives (SOLA) program should be included in the choice/market-driven system so that people have a choice to access or leave SOLA services. These settings are unique in that changes in staffing levels require specific legislative appropriations for funds and staff, as well as the current policy not to refuse services to anyone referred for services. These issues must be studied and thoroughly addressed before a final recommendation is made to include the SOLA program.

Service Stabilization for Group Homes

Group homes are homes for 2-6 people that are owned and staffed by providers. As with other settings where individuals share supports with others, the division may provide cost-of-care adjustments in order to ensure the stability of the supports available for the remaining individuals when one or more housemates have chosen to change providers (effective July 1, 2001). If after six months there are no new individuals choosing the group home service setting, a plan will be developed to ensure ongoing support for the individuals remaining in the group home affected by the change.

Future Role of the Residential Habilitation Centers (RHCs)

One of the primary objectives of the Stakeholder Workgroup is to build a viable recommendation that would allow the RHCs to be included in the choice/market-driven system along with other services in the support continuum. The Stakeholder Workgroup adopted a two-part recommendation:

- Collect and analyze respite data (by July 1, 2001)
 - Identify RHC short-stay capacity (scheduled respite, crisis support, transition support) and the extent to which it is being used
 - Determine short-stay respite preferences (if community options were made available)
 - Differentiate short-stay resource needs (i.e., how many vacant bed resources are needed to fund a crisis-related short stay?)
 - Designate fixed RHC short-stay resources needed, after the data is analyzed
- Implement informed choice:
 - The division will develop a 2001-2003 budget estimate to “offer choice for people whose assessed needs require the funded level of resources that are provided by the RHCs” (per RCW 71A.16.010). Funding will be requested for individuals to enter or exit the RHCs.
 - The division will develop a process to ensure informed choice, including a clear understanding of services available in the community and in RHCs, and the steps necessary to access those services (including an individualized plan of support for the services chosen).

The Stakeholder Workgroup will continue working during Phase III of the strategic plan to develop further recommendations regarding the future role of the RHCs.

Role and Administration of Adult Family Homes (AFHs)

Because the demand for individualized residential services is much greater than the funding available, many people who have more intensive support needs are using adult family homes. Adult family homes were developed by the Aging and Adult Services Administration (AASA) to meet the needs of an elderly population. AASA administrators and AFH staff have not been sufficiently trained to support individuals with developmental disabilities that require more intensive supports. It is therefore recommended that:

- Effective July 1, 2001, the division will improve services for individuals in AFHs by:
 - Providing DDD Specialty Training to 422 direct service staff working in AFHs serving individuals
 - Providing day programs for 500 people who have requested the service and are currently living in AFHs
 - Increasing the number of quality improvement visits for AFHs serving individuals from once per year to four times per year
- Beginning July 1, 2001 the division will work with AFH stakeholders to get input and direction for planning to transfer AFH administration from AASA to the division for AFHs exclusively serving individuals with developmental disabilities. Included in the transfer plans will be:
 - Development of separate licensing, certification, and complaint resolution functions
 - Rate structures compatible with service expectations
 - Piloting/evaluation activities
- Other areas for discussion and review include:

- “Grandfathering” safeguards to provide exceptions for exceptional situations
 - Changing description to “Shared Living Homes” with development of new WACs
 - Implementing Residential Guidelines and positive behavior support features
 - Expanding provider qualifications to include experience and education.
 - Providing individuals and their families/guardians with information regarding available shared support arrangements
 - Creating a process to focus on AFH size limitations and private bedroom availability
- The administration of AFHs serving multiple populations including individuals with developmental disabilities will remain in AASA.

The Stakeholder Workgroup will continue working during Phase III of the strategic plan to develop further recommendations regarding the future role of the AFHs.

Section 3 – Employment/Day Program Supports Workgroup Recommendations

“The Division of Developmental Disabilities will design and maintain an effective system of employment and day program supports and services that support and foster access to full time employment for all working age adults in inclusive settings or provide other meaningful opportunities to be contributing participants in the vital activities of community life.” (Phase I Report, page 29-30)

The following recommendations were organized into two general areas:

- Birth-to-Three/Early Childhood Services
- Adult Employment and Day Services

Birth-to-Three/Early Childhood Services Recommendations:

The Stakeholder Workgroup, regarding services for infants/children with developmental disabilities before they enter the school system at three years of age, approved five recommendations. This group of the youngest children is the fastest growing segment of people served through the division, outpacing forecasted funding. Services are provided to children who are either eligible under “Part C” of the federal Individuals with Disabilities Education Act, as an entitlement, or through the county government system, funded by state dollars. The federal program is managed by the Infant/Toddler Early Intervention Program (ITEIP) and administered by the division. As the two programs have differing eligibility requirements and outcome expectations, recommendations were prepared with input from a joint interagency workgroup formed to identify and resolve coordination and other service delivery issues facing these children and their families.

– Identification of Need

Identification of need will encompass several activities, including continuation of early identification activities, working with other state agencies to better educate the medical community, improving timely referrals, investigating a move to a common eligibility definition for federal and state-funded services, and continuing outreach to diverse communities:

- DDD/ITEIP will continue to work with individual counties to ensure that families have early identification, eligibility determination, and timely referral to appropriate service and support resources.
- DDD/ITEIP will work with the Medical Assistance Administration, Department of Health,

*The fastest
growing groups of
people served
through DDD are
infants and children
with developmental
disabilities under
the age of three.*

Department of Community, Trade and Economic Development, and Office of the Superintendent for Public Instruction (OSPI), along with statewide medical associations to develop a two-year project to better educate the medical community, including the development of publications suitable for distribution by local communities.

- Each local community will work closely with the medical community to assure that all pertinent medical personnel at hospitals, private and public clinics, and therapists know how to make early identification and timely referral.
- ITEIP will continue existing activities with the Medical Home Training and Resource Project.
- DDD will investigate the implications (program and fiscal) of developing one common eligibility definition.
- DDD will continue to make outreach to diverse communities a priority.

– **Connection to Support Services**

- Many families report frustration in being able to quickly and effectively connect to needed support services. The division will:
- Ensure that families will, upon identification of need, have timely information and connection to support/service options
- Ensure that local systems provide families with coordinated and non-duplicated support in acquiring needed services
- Establish a task force to address duplicative, conflicting roles within the DDD system

– **Supports and Services**

- While local systems allow flexibility, supports must be able to meet the needs of the child and their family:
- Supports and services will be created that are capable of meeting the specific needs of children and their families.
- Local systems will be supported to embrace the philosophy of natural environments.
- DDD will work with OSPI to enhance the funding of birth-to-three services by local school districts.
- DDD will include early childhood services in its system of quality assurance with regulations and guidelines explicit to the birth-to-three system.
- DDD will maintain the current early intervention policy of “no cost to families.”
- DDD will take the lead, working with other agencies, to develop a long-range plan to address the emergent fiscal crisis in the birth-to-three program.

– **Transition to School**

- Effective coordination is needed to assist children to transition into the school system when they turn three. Several changes are needed to ensure an effective transition to school:
- DDD will work with OSPI to develop a clear set of recommendations on how to improve transition to school for each child and their family.
- DDD will ensure that each local lead agency works cooperatively with their respective school districts to use a common evaluation and assessment process to enhance effective transition to school for the child and their family.
- DDD will work to provide a continuum of services that extends through the summer months to enhance effective transition to school.
- DDD will solicit input and assistance from parents and parent organizations in developing future service and support recommendations.

– **Local System Coordination**

- Local services are not always well coordinated and administered, particularly in regards to separating services on the basis of the different funding sources. The division will ensure a strong partnership with local lead agencies and county administration by:
- Providing leadership to develop information systems and “best practice” opportunities
- Providing assistance to support local flexibility while maintaining federal and state regulation compliance and consistency
- Identifying and working to resolve current contract administration barriers and conflicts prior to December 31, 2000

Adult Employment and Day Services Recommendations

Washington is the most successful state in the nation in the number of individuals gainfully employed. Employment and other successful “day” services are very important to the overall health and stability of individuals and their families/guardians. Community employment offers wages and benefits, status and opportunities for connection with coworkers and the community as a whole. Working also provides another important benefit to families. While their son or daughter is at work, parents and other family members may choose to work or pursue other interests. Employment affords the community at large the opportunity to experience first hand the capabilities and contributions made by individuals with developmental disabilities.

The Stakeholders recommend a new approach referred to as “Pathways to Employment” and “Alternatives to Work.” These recommendations were developed with the aid of the **White Paper on Individual Supported Employment** (September 1998), developed by the Washington Initiative for Supported Employment.

– **Pathways to Employment**

Each individual will be supported to pursue his or her own unique path to work, a career, or his or her contribution to/participation in community life. All individuals, regardless of the challenge of their disability, will be afforded an opportunity to pursue competitive employment. Work options will be based upon the individual’s interests. Employment in inclusive settings will be sought as the first option for all individuals. Sheltered employment settings will be supported by technical assistance to continue to improve services, facilities, outcomes, etc., as needed to provide access to the community for individuals who choose those settings.

The path may take a short time for some and could take years for others. The path will be determined by their personal plan and take into consideration their family and other personal circumstances. The needs of each individual will be fully supported, including when waiting for work, between jobs, or while in career exploration. Current data systems will be used as is or adapted to report outcomes for individuals.

– **Alternatives to Work**

For those relatively few individuals for whom work is not currently an option, or who are retired from work, there will be individualized alternatives to work, based on each person’s interests and preferences, focusing on community inclusion/connections and enhanced quality of life through active participation in community life.

The following three goal area recommendations are intended to facilitate the inclusion of all individuals into community life:

– **Systems Issues**

DDD will need to make several system changes in order to implement Pathways to Employment and Alternatives to Work, and to prepare for the eventual implementation of the choice and self-determination system including:

*Each individual will
be supported to
pursue his or her
own unique path to
work, a career, or his
or her contribution
to/participation in
community life.*

- Expand planning services
- Expand information/education services in all communities
- Enhance local system management (currently counties) ability to spend across fiscal years to maximize effectiveness of funding
- Develop a better method to ensure that funds for employment and planning services are sufficient for the county/community where the services will be purchased
- Increase coordination efforts between the division, Division of Vocational Rehabilitation (DVR) and local communities
- Revise billing and data systems to support the flexibility required by individual planning and budgets
- Transition to a “certified provider system” that affords individuals and their families/guardians greater information for selecting and changing providers

– **High School Transition**

DDD will take the lead in bringing together those entities responsible for facilitating transition from school to community work or activities, so that a coordinated program will be supported by OSPI, DDD, and DVR beginning at age 14, for all students eligible for division services, regardless of the significance of their disability:

- Each student will have an Individualized Transition Plan, unique to the individual, revised as needed. Personal agents or case managers will be available to assist the student and their family/guardian in preparing their Individualized transition plan.
- All students and their families/guardians will have access to transition coordination services, including community exploration.
- Every eligible student will be funded until age 21 by OSPI. The division will work with OSPI and the DVR to achieve this goal. The preferred option is to develop a process whereby OSPI would transfer the funds necessary to support 18 to 21 year old individuals in the workplace when they have completed their “classroom” educational goals.

– **Provider Stabilization**

In the future, individuals and their families/guardians will become the primary customers for certified providers. Individuals and their families/guardians will need access to a variety of supports from a choice of stable, capable certified providers.

Following are recommendations intended to support this transition:

- A provider certification system will be developed and implemented.
- Service rate guidelines to provide a basis for negotiations between individuals and their families/guardians in developing service agreements.
- Service rates need to be increased in order to stabilize provider availability and capability/quality.
- Funding incentives should be developed to ensure positive service and employment outcomes.
- Technical assistance is needed to assist providers to transition into the new market.
- Allocations for meeting needs of unserved individuals should be balanced with the need to provide stability services.

Section 4 –

Individual & Family Supports Workgroup Recommendations

“The Division of Developmental Disabilities will design and maintain a single, comprehensive system of individual and family supports.” (Phase I Report, page 30-31)

Currently there are several programs and services that address individual and family needs. These programs and services are available in the individual’s home. Funding is provided through both the federal and state government. Individuals and their families/guardians are faced with several challenges when using these programs and services. After reviewing all of the programs and services, essential criteria can be summarized as follows:

- Individuals and their families have identified the lack of information, training, and ongoing education as the main barriers to meeting their needs. Information must also be culturally/linguistically appropriate.
- Knowledgeable assistance in planning for and connecting to services must be available for individuals and their families/guardians.
- Access to an individualized budget, managed by individuals and their families/guardians, who are the “support experts,” is the most effective method to meeting needs.
- “Person-specific” support and resource development is necessary to support individuals and their families/guardians in the activities of daily living.
- The availability of qualified service and support providers is essential to building an effective, durable plan for support.
- Consistent statewide administration and management of services/supports will support individuals and their families’ values in determining use of funds and desired outcomes using a variety of supportive tools.

In order to move toward a single, comprehensive system of individual and family supports, compatible with the principles of choice and self-determination, the following five activities are recommended by the Stakeholder Workgroup:

Comprehensive Study of a Rate Structure Plan

The current system of rates for the provision of medicaid personal care and respite care services through individual and agency providers does not address any service, setting, geographic, or specialized training variables. While families cite individual provider recruitment/availability as a growing crisis, the effect of competitive wages, benefits, training opportunities, and other work conditions on the market has not been adequately studied.

The division will sponsor a comprehensive study, including an analysis of the spectrum of need, geographic and other variables, to result in a plan for a new system and approach to rate setting for individual providers. This undertaking should include participation from the Children’s Administration and other DSHS programs. Areas to be included in the study are as follows:

- Rate setting criteria used by each relevant DSHS program
- Factors affecting provider turnover rates and trends
- Evaluation of factors affecting service satisfaction and decisions by individuals and their families/guardians to change providers
- Geographic variables (cost, availability, etc.)
- Support variables (setting, location, age, intensity, complexity, etc.)
- Provider capability variables (experience, training, etc.)

Individuals and their families have identified the lack of information, training, and ongoing education as the main barriers to meeting their needs. Information must also be culturally and linguistically appropriate.

Agency Provider Pilot

The division will undertake a pilot project to study and test:

- Qualified provider recruitment and retention strategies
- Emergency response provider pool
- Indirect/administrative cost assessment
- “Employer of record” issues (training individuals and their families/guardians to be effective employers)
- Strategies for training, certification, and referral of individual and agency providers
- Contract dispute resolution, coordination of timely payments, and family assistance and training

Orientation and Training

As part of the division’s comprehensive information and education plan, the division will develop an orientation and training program for individuals and their families/guardians that includes:

- A comprehensive information package detailing all available division services and supports (including RHCs, sheltered employment services, Medicaid Personal Care, etc.)
- Locally available information on how to locate and evaluate qualified providers
- Information describing access to Personal Agent services
- Technical assistance resources
- Information and training available in multiple languages and media

Out-of-Home Respite Resources

Families and guardians are often faced with few or no choices when it comes to emergency or periodic respite opportunities outside of the individual/families’ home. Choices vary significantly based on geographic location. Barriers to accessing many possibilities, such as local community residential services, foster care, or RHC respite care, often prove to be insurmountable, particularly in emergent situations.

The division will work to increase the array of quality resources available for respite care outside the family home in all six regions, including:

- Use of RHCs or community residential services
- Specialized foster family care
- Possible respite care license for short-term out-of-home care for children should be investigated
- Develop information to include in the Children’s Administration new foster parent training, so these foster parents can be effective respite care providers for persons with developmental disabilities

Nurse Delegation Legislation

The division will develop legislation to extend the current nurse delegation statute to cover delegation of nursing tasks to individual providers caring for children and adults living in family home settings.* Provider capability variables (experience, training, etc.).

For more information regarding the *Strategies for the Future Long-Range Plan* report or the Division of Developmental Disabilities, please contact:

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